

## The ethics of disagreement between treating team and parents:

### The Zone of Parental Discretion

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## Overview

- 1. Background**
  - Clinical ethics service at RCH
  - International context

Ref: Gold, H., Hall, G. and Gillam, L. (2011). Role and function of a paediatric clinical ethics service: Experiences at the Royal Children's Hospital, Melbourne. *Journal of Paediatrics and Child Health*, 47: 632-636
- 2. Disagreement between parents and treating team**
- 3. When should parents' wishes be overridden?**
  - The best interests test
  - The Zone of Parental Discretion

## Clinical Ethics Service at RCH

- Case consultation
- Policy/procedure development
- Case review
- Education
- Research which grows out of and support all of the above

## Ethical practice at the RCH

The pyramid illustrates the components of ethical practice at the RCH, supported by external consultation and education.

## Structure of RCH Clinical Ethics Service

**Clinical Ethics Committee (CEC)**  
Chair: Dr Hugo Gold

**Clinical Ethics Response Group (CERG)**  
Team Leader: Dr Jenny Hynson

**Clinical Ethicist:**  
A/Prof Lynn Gillam


**Clinical Ethics Associate:**  
Dr. Clare Delany

## Members of Clinical Ethics Response Group


<b>Medical:</b> Hugo Gold Jenny Hynson Rod Hunt Neil Patel Karen Tiedemann Trevor Duke John Massie Gordon Baikie Kate Thomas Sue White Rob Roseby Lisa Barrow Andrew Court Zornitza Stark	<b>Allied Health:</b> Judith Sloan Lauren Andrew Debbie Kertesz Karen Wall Allison Baillie	<b>Nursing:</b> Nuala Kentish Julia McCoy Nicki Mountford Susan Skinner Nicole Milne Philippa Haydon Lyn Ireland
<b>Ethics:</b> Lynn Gillam Clare Delany Merle Spriggs Rony Duncan Georgina Hall		
<b>Legal:</b> Annabelle Mann		

### Process for Clinical Ethics Case Consultation

- Any staff member can refer (email, phone or page)
  - Family consent not needed, some clinicians inform family
- Options of
  - confidential discussion with Clinical Ethicist (+ ...)
  - Formal clinical ethics case meeting with Clinical Ethics Response Group
- Formal clinical ethics case meeting
  - Can be held at 24-48 hours notice
  - Brief case history and current situation to be provided in writing prior
  - Attended by
    - all available members of CERG (3 – 10+) attend
    - Clinical staff involved in care of patient (as invited by referring clinician) attend – aim to have all disciplines represented
    - CE present, chaired by CES team leader



- Documentation of meeting
  - prepared by Clinical Ethicist
  - Summary of main outcomes by email within 24 hours
  - Full notes of discussion within 1-2 weeks
  - Documentation goes to referring clinician, who decides how it will be used/ recorded /filed
  - Recommended approach is to make note of clinical ethics referral in medical record
- Follow-up
  - Referring clinician asked to inform CERG of progress
  - Further clinical ethics consultation can be requested
  - De-identified summary goes to CEC for review, and discussion of policy/procedure implications



### Referrals for clinical ethics case meetings 2005-2011


2005	5
2006	14
2007	6
2008	12
2009	16
2010	15
2011	16



### Context for Clinical Ethics Committees

In Australia, CECs are a hospital driven phenomenon, not set up or overseen by NHMRC or any other body

- No guidelines
- No set membership categories
- No pre-defined functions
- Each CEC or institution decides on scope, membership and functions



### Typical functions and membership of CECs

<h4>Functions</h4> <ul style="list-style-type: none"> <li>Policy formulation</li> <li>Education</li> <li>Review past case</li> <li>Advice on patient management – ethics case consultation / referral</li> </ul>	<h4>Membership</h4> <ul style="list-style-type: none"> <li>Doctors</li> <li>Nurses</li> <li>Lay persons</li> <li>Ministers</li> <li>Lawyers</li> <li>Administrators</li> <li>Ethicists</li> </ul>
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### International context

**Australia:** In 2000, approx 10-20% of hospitals had CECs<sup>1</sup>

- 2009, Victorian CECs forum – 10 CECs in Vic
- 2010, NSWHealth CECs meeting – 5 operating CECs in NSW

**UK:** in 2004, 19% of acute NHS trusts had CECs<sup>2</sup>

**US:** All hospitals have a clinical ethics process (CEC or clinical ethicist), as a requirement of accreditation

1. P. McNeill, "A critical analysis of Australian clinical ethics committees" *Bioethics* 15.6, 2001  
2. A. Slowther et al, "Development of clinical ethics committees", *BMJ* 328, 2004



## 2. Disagreements between treating team and parents



## Disagreements between treating team and parents

- Approx 70% of all clinical ethics case referrals involve disagreement between parents and treating team
- Difference in point of view, not always conflict per se
- Typical areas of disagreement:
  - Parents want to continue life-sustaining treatment, treating team think it is time to withdraw
  - Parents want a particular type of treatment, treating team thinks it is inappropriate
  - Parents do not want to tell child the truth about some aspect of their medical condition/care.
  - Parents do not want older child/young person involved in discussions/decision-making



## Example 1

- A is a 14 yo boy
- Has familial pulmonary arterial hypertension, diagnosed 5 years ago, commenced on oral therapy, slow decline, much more marked over few months
- Cardiologist recommends continuous intravenous prostacyclin.
- Family immigrated from Middle East 10 years ago, parents well-educated and speak English well
- A is oldest of 5 living children. 2 children have already died of same condition, one at 17, and one at 9 (anaesthetic complications at cardiac catheterisation)
- A's parents have been putting off a decision, and finally refuse intravenous prostacyclin – want to continue on oral therapy until lung transplant is available.



## Baby A

- Baby girl born with serious congenital heart anomalies, diagnosed at 4 weeks of age. Parents told the condition is treatable by a number of surgeries over the first ten years of the child's life, but cannot actually be fixed. The child will always be restricted in her activities, vulnerable to chest infections, and will eventually need a heart transplant to survive beyond teenage years. Once transplanted, she could be expected to live into 30s, 40s or beyond. But without the surgery, child will decline and die within a few months. Parents think it over, and decide not to have the corrective surgery, because their daughter would have a difficult and very restricted life, and would not be able to participate in the family. Family live on and run a large farm, and also run an outdoor adventure company. Older children in the family actively participate in farm and business activities. They ask for palliative care, and want to take their baby home.



## Child G

Child G is a 3 year old girl who has an undiagnosed neurodegenerative condition which has progressed rapidly over last 6 months, and now has kidney failure. She is fed by tube, has dialysis 4 times a week, and has recently been intubated and mechanical ventilated because of a respiratory infection. G has now been weaned off ventilation, but her breathing is still fragile, and an oxygen mask is used at night. G is minimally responsive and has very little movement – she groans, grimaces and moves her arms a little when procedures are being done; her parents say that she smiles at them and enjoys watching TV, but staff do not see signs of this.

The doctors believe that G's death is inevitable, and that continuing dialysis and artificial nutrition will just prolong her dying and make it more unpleasant for her. They raise the idea of stopping dialysis with her parents, who are devout Coptic Orthodox Christians. Her father absolutely refuses to countenance any limitation of treatment. He does not believe that she is dying – a definitive diagnosis has never been made, she has got past difficult times before, and he has had a dream in which God showed him G coming home to her family. He wants all treatment continued.



## Child F

Child F is a 9 year old boy who has deep lacerations to his upper arm from an accident at home. The bleeding was controlled by a compression bandage, and he received a large volume of IV fluid at a local hospital, before being transferred to specialist centre. The parents are Jehovah's Witnesses. The standard approach would be to give blood transfusion before surgery, giving a very high chance of saving the arm and restoring full function. Surgeons indicate it would be possible to not give blood, proceed to surgery to stop bleeding (ie to prevent the child dying from blood loss), and do whatever repair on the arm would be possible before low blood count meant surgery had to be stopped. Child F would survive, but could lose arm, or not regain full function in the arm. Parents refuse transfusion, want the other surgical option.



## The bottom-line ethical question

### 3. When should parents' wishes be overridden?

- a) The best interests test
- b) The zone of parental discretion test



### (a) The best interests test

- When parents wishes differ from medical recommendation/opinion, do whatever is in the best interests of the child
- Sounds straightforward, but isn't – a complex, multi-factorial and partly subjective judgment



### Making a judgement about best interests

"Best interests" is a summative judgement across all different aspects of a child's well-being

It is a judgement about the overall balance of

- **Pros** – expected benefits, advantages
- vs
- **Cons** – risks, burdens, disadvantages

The pros and cons cover:

- a range of domains – physical, psychological, emotional, etc
- Time periods – immediate, short term, long term
- In this context, one important aspect to consider is how child's social and emotional well-being will be affected by going against parents' wishes



A judgement about best interests often involves weighing up incommensurables (apples vs oranges)

Eg:

- Long terms risks vs short terms benefits
- function vs cosmetic appearance
- Physical health vs emotional well-being

There is no factual or scientific basis for doing this  
– it comes down to values, preferences, worldviews...

**"Best interests" is not wholly a medical/factual/objective judgement – has a subjective values component**



### Some problems with the best interests test

- "Best interests" implies finding the absolutely optimal outcome for child, maximising the child's interests/well-being – very hard to come to a decision about this
- Focuses entirely on the child – gives no clear place to parents, no recognition of their ethically special relationship to the child



### Parents' rights and well-being

Parents do not own or have absolute authority over their children (any more...).

However, they have sound ethical claims (rights) in relation to their children:

- The right to fulfill their parental obligation in the way that they judge best, according to their own values
- The right to meet their own needs: not to totally sacrifice their own interests for the sake of their children



## (b) Zone of parental discretion test

### Zone of parental discretion =

ethically and legally protected space where parents may legitimately make decisions for their children which are sub-optimal for those children (ie not best for them)

Rather than asking

**"What is in the best interests of the child?"**

Ask instead

**"Does this decision fall within the zone of parental discretion?"**



## Zone of parental discretion

### Best interests of child

Decision will produce *maximum* benefits

"good enough" interests

decision is contrary to child's interests (ie harmful)

Zone of parental discretion

No parental discretion



## Basis of zone of parental discretion

1. Parents have a moral claim to be decision-makers for their children, because of their right (within limits) to raise their children according to their own values. (Brock and Buchanan)
2. Intervention in the parents' decision is only justified when it results in **risk of serious harm to the child** – not simply when the decision does not *optimise* the child's interests.

(Brock and Buchanan, Diekema, Friedman Ross and more)



## The reason for the parents' decision is NOT the issue

Within the zone of parental discretion, reasons for parents' decisions may include:

- Their view of best interests of the child
- Religious beliefs
- Social and cultural norms and practices
- Consideration of their own interests
- Consideration of interests of siblings, or family as a whole

Their reasons are not relevant to the question of whether or not to abide by their decision

The only thing that matters is the effect of the decision on the child

*Is the decision likely to cause significant harm to the child?*



## Using the idea of the zone of parental discretion

1. What are the treatment management options for this child at this stage?
2. What are expected benefits and burdens/risks of each option
3. Which option is in the best interests of the child?
4. What do the parents want?
5. Does their decision fall within the zone of parental discretion?
6. If yes, no reason to go against it, even if it is sub-optimal for the child
7. If no, look for ways to change parents' decision – take legal steps as last resort

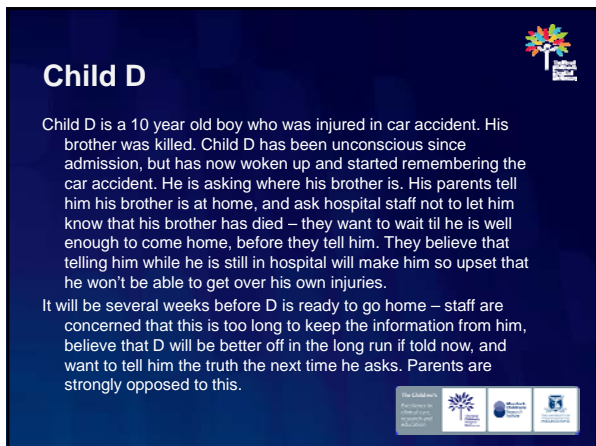
Assuming non-competent child



## A doubt...

- What if parents are not actually capable of exercising discretion? Ie if they are not able to understand, or misunderstand the effects on the child of the form of treatment that they want?
- Does Zone of parental discretion still apply?


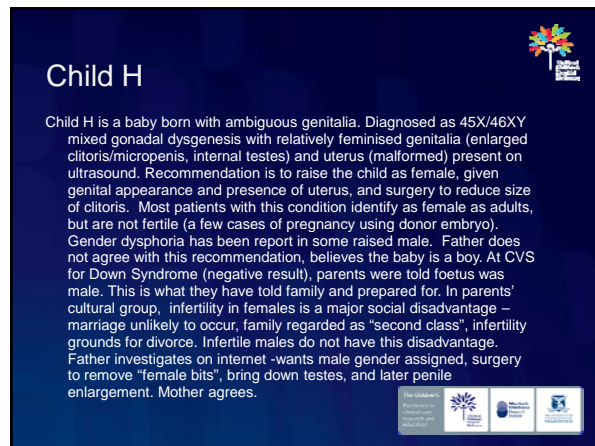




### Child D


Child D is a 10 year old boy who was injured in car accident. His brother was killed. Child D has been unconscious since admission, but has now woken up and started remembering the car accident. He is asking where his brother is. His parents tell him his brother is at home, and ask hospital staff not to let him know that his brother has died – they want to wait til he is well enough to come home, before they tell him. They believe that telling him while he is still in hospital will make him so upset that he won't be able to get over his own injuries.

It will be several weeks before D is ready to go home – staff are concerned that this is too long to keep the information from him, believe that D will be better off in the long run if told now, and want to tell him the truth the next time he asks. Parents are strongly opposed to this.

### Child H

Child H is a baby born with ambiguous genitalia. Diagnosed as 45X/46XY mixed gonadal dysgenesis with relatively feminised genitalia (enlarged clitoris/micropenis, internal testes) and uterus (malformed) present on ultrasound. Recommendation is to raise the child as female, given genital appearance and presence of uterus, and surgery to reduce size of clitoris. Most patients with this condition identify as female as adults, but are not fertile (a few cases of pregnancy using donor embryo). Gender dysphoria has been report in some raised male. Father does not agree with this recommendation, believes the baby is a boy. At CVS for Down Syndrome (negative result), parents were told foetus was male. This is what they have told family and prepared for. In parents' cultural group, infertility in females is a major social disadvantage – marriage unlikely to occur, family regarded as "second class", infertility grounds for divorce. Infertile males do not have this disadvantage. Father investigates on internet -wants male gender assigned, surgery to remove "female bits", bring down testes, and later penile enlargement. Mother agrees.




- **Child A – MRI**
- Child A, 4 year old boy, brought by parents to emergency dept with a headache. Mild viral illness diagnosed – not and fluids recommended. Next day they are back again, headache persisting. Parents arrange next brain MRI. Doctor says no medical reason – headache and vomiting. Parents know a family young son was recently diagnosed with a brain tumour – they know it's not rational, but they are afraid and really want the MRI. They are willing and able to pay.
- **Child B – best condition**
- **Child C – early discharge**
- Child C, 2 year old girl, has been in hospital for appendectomy. Family lives in small country town 3 hours drive from the city where the hospital is. Child C has an infection post-op but has eaten reasonably well, and is expected to go home tomorrow. Parents approach doctors, advise that they want to take their daughter home tonight, so they can all go to watch her sister's school play at the local football field the next day. Doctor explains that although C is doing well, post-op night in hospital for respiratory or haemorrhage risk for the sake of the infection in order control. Parents say that the football field is very important to the whole family, and they want to go tonight, even if it is late.
- **Child D – brother killed (possible disease, non-medical, refusal, parents' view of best interests)**
- Child D is a 10 year old boy who was injured in car accident. His brother was killed. Child D has been unconscious since admission, but has now woken up and started remembering the car accident. He is asking where his brother is. His parents tell him his brother is at home, and ask hospital staff not to let him know that his brother has died – they want to wait til he is well enough to come home, before they tell him. They believe that telling him while he is still in hospital will make him so upset that he won't be able to get over his own injuries. It will be several weeks before D is ready to go home – staff are concerned that this is too long to keep the information from him, believe that D will be better off in the long run if told now, and want to tell him the truth the next time he asks. Parents are strongly opposed to this.
- **Child E – epinephrine (significant but not life/death, medical, refusal, parents' view of best interests)**
- Child E is a 9 year old girl with advanced metastatic cancer. She has bony tumours, which have been causing her significant pain. She has needed increasing doses of a pain relief drug called morphine. The oncology team has said that another round of chemotherapy is highly unlikely to do any good, and morphine may kill it. A friend of a parent's said that a friend had found a specialist, called Helen and Richard, who have had chemotherapy off market. Helen is the treatment manager at a cancer centre. E's parents bring in many bags of funds to be given up and a cash bond, and ask oncologist that morphine must be stopped, because the specialist says it will interfere with the herbs. They present a signed document stating morphine is to be given to E, and that pain is to be managed on a further round of chemotherapy.
- **Child F – JW: sub-optimal surgery for arm injury (significant but not life/death, medical, refusal, religious beliefs)**
- Child F is a 9 year old boy with his right shoulder in the upper arm from an accident at home. The shoulder was controlled by a compression bandage, and he received a few weeks of IV fluid at a local hospital. Before being transferred to specialist centre. The problem was, although F's shoulder was controlled, it was not possible to get a long term transfusion before surgery, giving a very high risk of stroke the usual transfusion. Surgeon decides it would be possible to not give blood, proceed to surgery to stop bleeding (to prevent the child going down blood tests), and do whatever repair on the arm would be necessary, because the transfusion is to be stopped. Child F would survive, but could lose arm, or not regain full function in the arm. Parents refuse transfusion, want the other surgical option.
- **Child G – ventilation (life/death, medical, demand, non-belief in medical facts)**
- Child G is a 2 year old girl with the rare autosomal recessive disease, Cystic Fibrosis, which has progressed rapidly over her 2 months, and now has kidney failure. She is fed by tube, has dialysis 4 times a week, and has recently been intubated and mechanical ventilated because of a respiratory infection. G has now been weaned off ventilation, and her breathing is still fairly good, and so oxygen levels is used at night. G is extremely responsive and has very little discomfort – only grunts, groans and moves her arms a little when procedures are being done, her parents say that she smiles at them and enjoys watching TV, but staff do not see signs of this. The doctors believe that G's condition is reversible, and she continues to have good lung function, but still requires low dose antibiotics and corticosteroids any time she has the usual respiratory infection. Her doctors believe that she is doing – a suitable diagnosis has never been established, and she is doing better, and is in fact at home in her family. G is followed from G's country home to her family, she has no treatment requirements.
- **Child H – boy or girl? (significant but not life/death, medical/non-medical, sort of refusal, cultural beliefs/best interests)**
- Child H is a baby born with ambiguous genitalia. Diagnosed as 45X/46XY mixed gonadal dysgenesis with relatively feminised genitalia (enlarged clitoris/micropenis, internal testes) and uterus (malformed) present on ultrasound. Recommendation is to raise the child as female, given genital appearance and presence of uterus, and surgery to reduce size of clitoris. Most patients with this condition identify as female as adults, but are not fertile (a few cases of pregnancy using donor embryo). Gender dysphoria has been reported in some raised male. Father does not agree with this recommendation, believes the baby is a boy. At CVS for Down Syndrome (negative result), parents were told foetus was male. This is what they have told family and prepared for. In parents' cultural group, infertility in females is a major social disadvantage – marriage unlikely to occur, family regarded as "second class", infertility grounds for divorce. Infertile males do not have this disadvantage. Father investigates on internet -wants male gender assigned, surgery to remove "female bits", bring down testes, and later penile enlargement. Mother agrees.




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